

*N*ational Agenda for Children
with Special Health Care Needs

ACHIEVING THE GOALS
2000

FORWARD

April 1990 interview as I prepared to leave my position as Surgeon General of the United States Public Health Service, I was asked the following question: In your tenure as Surgeon General, what are you proudest of. My response then and still today is the following:

I'm personally proudest of the things I've done for children with handicaps. We've started a new system of family-centered, community-based, comprehensive care for kids with special needs. We've had workshops all over the country to adopt a new approach to understanding kids with handicaps, to learn how they should be cared for, and to include their families as part of the treatment.

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It is therefore a special pleasure for me to contribute the foreword for the revision of the National Agenda established during my tenure in the 1980s and continuing today as the philosophy underlying and guiding the principles of care for children with special health care needs and their families.

The principles of family-centered, community-based care began to emerge as a national vision in 1982 at my Surgeon General's Workshop at the Children's Hospital of Philadelphia. At that conference, we addressed the issues of children dependent on technology, and we led the nation in developing programs to ensure that these children could be successfully cared for at home rather than undergoing long-term hospitalization. The models we developed for home and community-based care supported the overall health, psychosocial, and developmental needs of children and their families. They also ultimately showed cost savings of \$1,200 to \$1,500 a month.

We have continued to learn lessons from these and similar programs for special populations of children and, as a result, we have moved from a categorical to a non-categorical paradigm of service delivery, from medical to more functional definitions of disability, from deficit perspectives to strength perspectives, from clinical to family-centered philosophies, and from isolated to integrated models of providing services. Over and over again, we have learned that a community system of care, comprehensive and coordinated around the needs of children and families, though difficult to achieve, is absolutely essential to the efficient provision and utilization of resources at the community level.

So clear was this lesson that in 1987 we initiated Campaign '87, which outlined seven action steps that drew our efforts together, supported the progress we had made, and charted a strong future course. In 1988, my Surgeon General's Conference, co-sponsored by the Maternal and Child Health Bureau, the American Academy of Pediatrics, and over 70 professional and voluntary organizations, endorsed a National Goal to Build Systems of Care for Children With Special Health Care Needs and Their Families. Two years later, in 1989, we translated the principles of the national goal into legislation. And in 1991 we included in the National Healthy People 2000 Objectives a goal to establish these new systems of service in 50 states by the year 2000.

I am happy to report great progress in reaching our goal. In addition to the accomplishments noted above, the National Agenda has influenced the legislation of virtually every federal program designed to serve children with disabilities and their families. As a result, the principles upon which this agenda is built have been put into operation and are now practiced at the state level through legislation, state program policies, and support offered to communities. And these communities, in partnership with the children and families they serve, are creating new and innovative ways of organizing and integrating services.

Currently, new systems are emerging within the general health care arena, and existing systems are being redesigned in response to reform in both the public and private marketplace. Increasingly, managed care is becoming a major provider of health and medical services for children with special health care needs. While these trends do not change the principles upon which the National Agenda is based, they do necessitate a revision and updating of both the agenda itself and of its accompanying action plan.

The new National Agenda recognizes these changes and looks for opportunities to ensure that the new, emerging systems are fully responsive to children with special health care needs and their families as we continue our efforts to reach our goal by the year 2000.

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National Agenda for Children with Special Health Care Needs

In the new environment within which health care is taking place, this revised National Agenda for Children with Special Health Care Needs builds on past experiences and successes to assure that policies and programs are in place to guarantee that children have access to quality health care, providers are appropriately trained, financing issues are equitably addressed, and families play a pivotal role of how services are provided to their children. The following seven action steps are proposed:

1. Sustain the national consensus for building community-based and family-centered systems of care for children with special health care needs.
2. Stimulate professional preparation programs to provide new skills needed by providers in changing delivery systems.
3. Support the development of models that resolve cost and utilization issues for children with special health care needs.
4. Provide leadership in the establishment of quality assurance programs for children with special health care needs in managed-care settings.
5. Identify and support the implementation of models of family participation in managed-care settings.
6. Develop strategies for improving data and evaluation activities to monitor the success of the National Agenda for Children with Special Health Care Needs.
7. Integrate managed-care programs within the community system of services.

A Call for Action

We are once again asking all of our partners to join in a common effort to develop and improve local systems of care for children with special health care needs and their families. Our broad goals for the Year 2000 are twofold:

- To sustain, improve, and fully implement coordinated local systems of care that are family-centered
- To integrate managed-care programs into these community systems.

As we work towards these goals, each partner involved in this collaborative effort can contribute uniquely to this agenda in the following ways:

- * *Families* can participate in building strong grass roots advocacy initiatives, and in developing effective family coalitions at the national, state, and local level. In addition, we ask families to take the systems and approaches that have been developed over the last several years and advocate for them in managed-care programs. Finally, we call upon families to be knowledgeable and effective users of health care and related services.
- * *States* must continue to carry out their legislative responsibilities to develop community systems of services, to provide or arrange for uncovered services, and to measure progress in systems development. In addition, we call upon states to monitor the way in which managed care is integrated into current systems to assure effective linkages. Finally, we call upon states to take the lead in defining new roles and responsibilities for, state programs.
- * *Communities* can assure that all children with special health care needs have access to a medical home. In addition, communities can develop mechanisms at the local level to bring managed-care providers together with family advocates as well as with other elements of the community system in order to identify and build upon the strengths of each community, thereby enhancing the ability of the local system to positively impact the quality of families' lives.
- * *Service Providers* can learn about and help define new arrangements with public and private providers and they can take responsibility for assuring that these arrangements are developed in the best interests of children with special needs and their families. In addition, we call upon managed care providers to reexamine service delivery methods, considering implications for both cost effectiveness and benefits to the child and family.
- * *Managed-Care Entities* can become familiar with the principles of family-centered, community-based systems of care and learn about models that are both cost efficient and in keeping with these principles. They can also become major partners with us in assuring that children and their families are well served in managed care settings and that effective linkages are made with other community providers.
- * *Federal and State Partners* can provide responsible leadership and policy development and can learn more about the roles that partners in public health, education, and social services must play in order to coordinate with one another and with managed care entities.

Merle McPherson